

Disability Issues

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Providing Model Care for Spinal Cord Injury, Traumatic Brain Injury, and Burn Injury Patients

By Julie Voegelin

Spaulding Rehabilitation Network is one of two organizations nationally to be awarded the prestigious designation of having 3 Model Systems: Spinal Cord Injury (SCI), Traumatic Brain Injury (TBI) and Burn Injury Rehabilitation. This honor is awarded by the National Institute on Disability and Rehabilitation Research (NIDRR), a division of the US Department of Education, and focuses on three main programmatic areas: Continuum of Care, Research and Education Dissemination.

This means that Spaulding's programs in SCI, TBI and Burn Injury Rehabilitation have been recognized as Regional Centers of Excellence and national models of care. Not only is this an acknowledgement of the excellent clinical care that is already provided, but means that patients will continue to receive model care in inpatient, outpatient, home and community settings. Simply put, patients admitted to a model system of care will not "fall through the cracks."

Spaulding did not receive the model systems designation alone; its acute care partners for SCI and TBI are MGH and BWH, and for the Burn Program, its acute care partners are MGH and Shriners Hospital for Children. The Spaulding TBI Model System has two rehabilitation facilities in its continuum, Spaulding Boston and Spaulding

Hospital Cambridge. This establishes the core network for all three programs; although patients admitted to the Spaulding TBI, SCI or Burn Programs from any acute care hospital will receive the benefits of the Model Programs.



Photo: Topher Cox

The first pillar of a Model Systems program is the continuum of care, where patients are closely followed through the acute, inpatient rehabilitation, outpatient, home care and community settings. A nurse care manager or designee follows patients through the continuum, ensuring that patients have access to the services they need, when they need them. They help to identify resources for ongoing medical care, housing, vocational support, social support and overall community re-integration resources. This is especially

helpful for patients who have experienced a significant disability as a result of a TBI, SCI or Burn.

The second pillar is research, which provides a significant benefit to patients enrolled in a Model System. Each program contributes data to a well-established, national database where practitioners have access to demographic and outcomes data from thousands of patients with similar diagnoses. This allows clinicians to have a better understanding of a patient's care needs and prognosis based on their specific diagnosis. The databases have also resulted in changes in the way care is provided, and what areas are important for further research.

For example: kidney problems, including Urinary Tract Infections, used to be a leading cause of death for SCI patients. The SCI Model Systems database, which was established in 1973 and contains information on over 30,000 patients, helped to identify this mortality trend. Because this trend was identified, Urology care for SCI patients has increased significantly, and now kidney problems have dropped to the 4th leading cause of death.

In addition to enrollment in the national database, each Model System conducts their own site-specific research, and collaborative research projects with one

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or more partners. Any patient admitted to the Spaulding SCI, TBI or Burn Program can choose to be enrolled in research studies if they meet the eligibility criteria.

The final pillar of a Model System program is the dissemination of education — for patients, families, providers and policy makers. Because NIDRR is a division of the Department of Education, this is a critical component of a Model Systems program, and Spaulding must meet the stringent criteria for ongoing education. The types of information provided include medical issues, care needs and resources available to patients and caregivers. It is delivered in multiple mediums

to ensure that individuals with any type of disability can access it.

The Spaulding model system programs provide a variety of information through brochures and flyers, websites, lecture series, podcasts, blogs and interactive learning modules (ILMs). Each program is at a different level of maturity in their designation, so focus on each pillar continues to grow.

Spaulding is honored to be recognized for its outstanding Model Systems care, and is firmly committed to maintain this designation into the future.

For more information on the Spaulding programs, please contact:

SCI Model System

Program Director: Leslie Morse, MD
Contact: Helen Stott,
Research Coordinator
617-952-6173 • www.sh-sci.org

TBI Model System

Program Director: Joe Giacino, PhD
Contact: Cecilia Carlowicz,
Research Assistant
617-952-6309 • www.sh-tbi.org

Burn Model System

Program Director: Jeffrey Schneider, MD
Contact: Katie Mathews,
Research Assistant
617-952-6313 • www.bh-bims.org

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Julie Voegelin, MS, is Director of Referral Marketing for the Spaulding Rehabilitation Network and Partners HealthCare at Home. She is a licensed Speech-Language Pathologist and has worked in the rehabilitation field for over 20 years.

Love and Intimacy Corner

Ask Ms. Love



Dear Ms. Love,
I have met a person I have gotten close to, very close. The person is suggesting we move into a physical relationship. While I watch my diet and exercise when I can, I don't feel the same way about my body as my partner feels about their body; I have a disability and feel self-conscious about what my special person will think of my body. This person brought up a physical relationship again yesterday. Any advice?

Signed, Fully Clothed

Dear Fully Clothed,
I consider every lump, bump, scar and more that makes up my body now as just a part of who I am. Sure, I could eat better, I should exercise more, but I want to be loved for me, the way I come. Trying on a new bathing suit can hit me over the head with how my body looks, but people who don't have a disability have issues with how they look in a bathing suit, too. And I am still going to don a bathing suit and enjoy all that summer activities can bring.

What makes you feel sexy? Playing a favorite song? Cooking together with your loved one? Wearing new underwear you bought for the occasion? Showering together? You are perfect the way you come, no matter what your health or disability. Discuss your needs with the person you love, and let them help you feel beautiful, inside and out.

My best to the two of you,
Ms. Love

The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at DL.LoveandIntimacy@gmail.com Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.

NOTE: See the Information Brief, **Sunday Afternoon at the Movies**, for movies related to sexuality and intimacy.

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its Best Hospitals survey with a #5 ranking in 2011. For more information, visit www.spauldingnetwork.org.

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From the Editor

Dear Readers,

During these lazy, hazy days of summer, we bring you a newsletter with the vibrant energy of holistic living, advocacy, and sexual intimacy! Yes, we are talking openly about love, sex and relationships in our new column – the **Love and Intimacy Corner** – and we want to hear from you, our readers. What questions do you have? What topic areas are you interested in? Ms. Love is in the house and ready to respond!

To complement our Love and Intimacy Corner, we have received permission for our readers to participate in the National Association of Social Workers' program, **Sunday at the Movies**. This Fall, there are two movies related to sexuality (*The Sessions*) and love at the end of life (*Amour*). I've seen both movies and was deeply moved by their authenticity.

Holistic living is the cornerstone for the **Model System programs** that are in place for individuals with spinal cord injury, traumatic brain injury and burn injury. So often, the focus is only on treating and rehabilitating the physical body. The Model System offers a continuum of care, where patients are followed through inpatient, outpatient, home and community settings. It is exciting to see this care being offered to support the whole person as part of their rehabilitation program. It is my hope that the learning and education gathered from these three injuries can be leveraged to benefit all people with disabilities.

As we look toward the Fall, you may want to consider getting involved in local or international advocacy efforts to improve the lives for all who are living with disabilities. The grass-roots community, **ADAPT**, is 30 years strong this year! They continue to organize disability activists who play a vital role in influencing legislation that ensures the civil and human rights of individuals with disabilities. Or, you may find it fascinating to become more involved with understanding and advocating disability rights internationally. There's an update on the current status of The Convention on the Rights of Persons with Disabilities (CRPD) and a comprehensive list of international disability organizations for you to explore.

Before summer is over, do take some time to explore the **state parks, beaches and playgrounds** that have recently enhanced their accessibility. I look forward to this list continuing to grow until we don't need a list because every place is accessible.

Marianne DiBlasi, Editor

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To view *Disability Issues* on-line go to
www.workwithoutlimits.org/DisabilityIssues



Free Our People: ADAPT Protests in DC

By Kate Ryan

Did you know that the disability rights organization, ADAPT, turns 30 this year? Well, they do! They have been protesting and protecting our civil rights for 30 years. This past April, they had a demonstration in Washington, DC to urge lawmakers, specifically the Housing and Urban Development department, to enforce the Supreme Court ruling *Olmstead*, which gives people the right to live in their own homes with personal care aides instead of in nursing homes.

Allegra Stout, Kevin Heaton and Ashley Schick are all members of a budding ADAPT group based at the Boston Center for Independent Living. They participated in the DC protests and spoke to *The AccessLetter* about their experiences.

Of course, the first thing that was asked about was the arrests. Allegra says that, "The arrests occurred at our first action, when we rushed through a police line to protest at the White House front gate because of Obama's failure to follow through on promises to the disability community. We chanted there and non-violently protested for perhaps an hour. Meanwhile, the Secret Service finished negotiating with ADAPT leaders. Eventually they told us that we would all be given citations with \$100 fines, but that they would let us go...Forty-one people were arrested, and the rest of the 200 or so ADAPTer supporters us from across the street."

Both wheelchair users and non-wheelchair users were arrested, and this was only on Monday! On Tuesday, more protests followed at the Department of Housing and Urban Development. HUD was being much too slow about telling housing providers that they had to comply with *Olmstead*. Thanks to the brave work of the ADAPTer, by the end of the day, they got a promise that the guidance would come out within a month, and it did come out, in early June.

The third day saw protests at the Department of Labor over people with disabilities being left out in personal care attendant regulations. The ADAPTer's spent a long, hard day there but, although they came quite close, nobody got arrested when they blocked entrances and parking lots. They did, however, get the attention of a lot of people and made their cause well known.

All three people said that they absolutely feel they made a very real difference, and would happily participate in further ADAPT events. Allegra Stout is in charge of the fledgling Boston group, and you can reach her at astout@bostoncil.org. To find out more, and to see photos from the protests, please visit ADAPT's website at www.adapt.org.

Kate Ryan has a master's degree in interdisciplinary studies with a focus on disability studies. She currently works as a personal care aide while searching for work in the disability field.



Photos: Courtesy of ADAPT Website 2012

Resurrection of the Convention on the Rights of Persons with Disabilities (CRPD)

By Marianne DiBlasi and Carolyn Thompson

The Convention on the Rights of Persons with Disabilities (CRPD) is an international disability treaty that was inspired by U.S. leadership in recognizing the rights of people with disabilities. The CRPD is a vital framework for creating legislation and policies around the world that embrace the rights and dignity of all people with disabilities. The Americans with Disabilities Act (ADA) was the model for the CRPD, where values of independence and respect, and concepts of reasonable accommodation are echoed throughout the treaty.

The United Nations adopted the Convention on the Rights of Persons with Disabilities in 2006. The CRPD was officially opened for nations to sign on March 30, 2007 and America signed the CRPD on July 30, 2009 - joining more than one-hundred and forty other nations that had already signed the treaty. Signing of the treaty creates the obligation to not violate the object and purpose of it, yet State Parties are not bound to uphold the specific obligations of the CRPD until they ratify it. One hundred and three nations have ratified the Convention on the Rights of Persons with Disabilities, thus making it a law for their country.

On December 4, 2012 the United States Senate considered the ratification of the CRPD but fell 5 votes short of the super-majority vote required. Senate Democrats are trying to resurrect a United Nations Treaty on the Rights of Persons with Disabilities. The media coverage of the Senate's failure to ratify the disability treaty in December 2012 has been overwhelming and the CRPD's Senate leaders, the disability

community and its allies remain committed to bringing the treaty up in the 113th Congress.

On September 23, 2013 the General Assembly will hold a High-level Meeting on Disability and Development, with the overarching theme, "The way forward: a disability inclusive development agenda towards 2015 and beyond", at United Nations Headquarters in New York.

Participants of the meeting will comprise of a plenary meeting and two consecutive informal interactive round tables. Participation in each round table will include Member States, observers and representatives of entities of the United Nations system, as well as representatives of civil society, organizations of persons with disabilities and the private sector.

The High-level Meeting will result in a concise, action-oriented outcome document in support of the aims of the Convention on the Rights of Persons with Disabilities and to include persons with disabilities in the Millennium Development Goals after 2015.

Please visit the resources listed below to learn more about international disability organizations.

Carolyn Thompson is a Disability Consultant to Faith Communities.

Marianne DiBlasi is Editor of Disability Issues and Founder of Disability Visibility.

Internationally Focused Disability Organizations

United Nations Enable (SCRPD) • www.un.org/disabilities
The official website of the Secretariat for the Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) • www.un.org/disabilities/convention/conventionfull
A direct link to the full text of the CRPD

United Nations Millennium Development Goals (MDGs)
www.un.org/millenniumgoals
Represents a concerted effort to address global poverty. There is a striking gap in the current MDGs and their inclusion of persons with disabilities.

International Disability Alliance (IDA)
www.internationaldisabilityalliance.org
Promotes the rights of persons with disabilities throughout the UN system, with a special attention in the areas of human rights & social development.

US International Council on Disabilities (USICD) • www.usicd.org
Promotes the inclusion of disability perspectives in U.S. foreign policy and aid and provides opportunities for domestic disability rights organizations to interface with their international counterparts.

World Report on Disability • www.who.int/disabilities/world_report
Provides global estimates of persons with disability in an unprecedented overview of the status of disability around the world. Full and summary versions of the report are available in multiple accessible formats.

Disabled Peoples' International (DPI) • www.dpi.org
A network of national organizations of disabled people established to promote human rights of disabled people through full participation, equalization of opportunities and development.

Mobility International (MIUSA) • www.miusa.org
Empowers people across disabilities around the world to achieve their human rights through international exchange and international development.

World Institute on Disability (WID) • www.wid.org
An internationally recognized public policy center founded to eliminate barriers to full social integration and increase employment, economic security and health care for persons with disabilities.

Enhancing Accessibility at Massachusetts State Parks

The Department of Conservation and Recreation's (DCR) Universal Access Program is dedicated to providing outdoor recreation opportunities in Massachusetts State Parks for visitors of all abilities. Here are some exciting accessibility improvements that will be introduced this year to make your visits to our local parks even more enjoyable:



Skinner State Park in Hadley MA has a wheelchair accessible viewing deck at the Summit House atop Mount Holyoke. This spectacular view of the Connecticut River

Valley is something you should not miss!

Mount Tom State Reservation in Holyoke MA has a new accessible trail leading to a viewing bridge on Lake Bray that opened this summer.



Mt. Greylock State Reservation in Lanesboro MA has several new accessible interpretive and signage projects that will enhance your visit to Massachusetts' highest peak. The newly installed exhibits in the visitor's center combined with new interpretive signage at the summit will certainly augment the overall enjoyment of being at this extraordinary park.



Scusset Beach in Sandwich MA has a new accessible boardwalk over the dunes. This, combined with last year's addition of two new beach wheelchairs that will allow you to roll into the water, should make your beach days a memorable event.



For information on DCR's Universal Access Program and MA State Park information, visit www.mass.gov/dcr/universal_access/

Sunday Afternoons at The Movies

The MA chapter of the National Association of Social Workers (NASW) sponsors *Sunday at the Movies* as a way for social workers to earn continuing education credits. They have generously offered to open their movies to the general disability community. Each program features an introduction, film presentation, and a facilitated discussion after the film.

The NASW movie series is held from **2:00-5:30 p.m. at the Studio Cinema in Belmont, 376 Trapelo Road, Belmont, MA.** The theater is accessible. Movies are Free for all non-NASW members who are not requesting CEU credit. No need to pre-register, just arrive on time!

Ben X

September 22, 2-5:30pm

Film Synopsis: Ben is an autistic teenager who avidly plays his favorite online computer game, trying to train himself for the harsh real world of a technical school, which is for him, a daily kind of hell. As the horror of being a constant subject of bullying escalates, Ben devises a plan involving suicide, which forces his online friend to intervene.

Amour

(French film with subtitles)

October 20, 2013, 2-5:30pm

Film Synopsis: Georges and Anne are a couple who are enjoying life in their eighties. Anne suddenly has a stroke and their lives are never the same. That incident begins Anne's harrowingly steep physical and mental decline as Georges attempts to care for her at home as she wishes.

The Kid with a Bike

(French film with subtitles)

November 24, 2-5:30pm

Film Synopsis: When 10 year-old Cyril's father abandons him, he obsessively searches for his bicycle - placing his last bit of hope in this symbol of their relationship. Almost by accident, he becomes the ward of a kind hairdresser, who seems surprised to find herself so determined to help him.

The Sessions

December 8, 2013, 2-5:30pm

Film Synopsis: Mark O'Brien has had polio since age 6 and uses an iron lung for hours each day. Now at age 38, this devoted Catholic faces his sexual nature. With the priest's blessing, Mark hires Cheryl Cohen-Greene, a professional sex surrogate. Sex and intimacy lead to emotional nuance and deep feelings for Mark and Cheryl. Inspired by a true story.



SMILE Mass – Helping to Create Accessible Play Spaces for All

SMILE Mass (Small Miracles in Life Exist) is a non-profit in Sudbury MA that was created in 2009 by Lotte Diomede and Susan Brown, parents of a child with disabilities. For more information, visit www.smilemass.org

Accessible Playground in Sudbury

The goal of the SMILE Sudbury Playground Project was to create the first accessible playground for the MetroWest community. This initiative came about when Lotte Diomede, a Sudbury resident with a child with multiple disabilities, became aware of the limitations when trying to access the parks and play areas in Sudbury.

With the fundraising assistance of SMILE, Sudbury now has a completely accessible play area that allows anyone with disabilities to be a part of a community area and develop physically, socially and emotionally. Children and young people without disabilities have an opportunity to develop tolerance, awareness and compassion for others in a fun and socially positive atmosphere.

The beautiful and award-winning SMILE Sudbury Playground is located across the street from 40 Fairbanks Road at the intersection of Hudson Road and Fairbanks in Sudbury MA.

The SMILE Beach Project

On Friday, June 28, SMILE Mass donated 20 beach wheelchairs to public beaches on Cape Cod. This is the second part of Phase One of this project, which is to bring 100 Mobi-Chairs to the beaches of Cape Cod. In June 2012, they delivered 20 Mobi-Mat® Beach-Access chairs to 20 beaches in 12 towns on Cape Cod. On June 28, 2013 they delivered 20 more!

The Mobi-Mat® Beach-Access chair is a high quality, amphibious rolling beach chair that provides a seamless transition from the parking lot, across the sand, and right into



the water — allowing anyone with special needs to access the beaches of the Cape. To see a chair in action, visit www.smilemass.org/mobi-chair.

Thanks to SMILE Mass, beaches in the following towns are more accessible: Barnstable-Hyannis, Buzzards Bay, Chatham, Dennis, Falmouth, Harwich, Mashpee, Provincetown, Sandwich, Yarmouth, and Wellfleet as well as to the Long Pasture Wildlife Sanctuary, a Mass Audubon property in Barnstable.

RAISE THE BAR HIRE!

WorkWithoutLimits
FIRST ANNUAL CONFERENCE
10.08.13

SAVE THE DATE

WHEN
Tuesday, October 8, 2013

WHERE
Four Points by Sheraton
1125 Boston-Prov. Tpk (Rte. 1)
Norwood, MA 02062

TIME
Registration 8am - 9am
Program 9am - 4pm

WHO
Employers, employment service providers, state agencies, people with disabilities and family members are invited to attend.

SPONSORED BY:

TJX THE TJX COMPANIES, INC. **Fidelity** INVESTMENTS **MASSACHUSETTS**

Join Work Without Limits to learn how you can raise the bar higher to advance the employment of people with disabilities. Featuring exhibitors, networking opportunities, and break-out sessions for a full day of learning, sharing and engaging with industry leaders.

KEYNOTE: Keith Wiedenkeller, Senior Vice President and Chief People Officer, AMC Entertainment

Hear about AMC Entertainment's competitive work program for individuals with autism and other disabilities that has been put into operation in over 300 AMC theatres nationwide.

For information about Sponsorship & Exhibitor opportunities or general questions, please contact Jason Stanislawzyk, 508-856-3646 jason.stanislawzyk@umassmed.edu.

WorkWithoutLimits Made possible by: Work Without Limits, a statewide network of engaged employers and innovative, collaborative partners that aims to increase employment among individuals with disabilities. Our Goal: To position Massachusetts as the first state in the nation where the employment rate of people with disabilities is equal to that of the general population.

Visit www.RaiseTheBar2013.org to Register!

Expanding Knowledge and Connections at the Annual Consumer Conference

by Jamie Mello

The Annual Consumer Conference took place this year on June 20th and 21st at the Four Points by Sheraton Hotel in Norwood Massachusetts. The Annual Consumer Conference was co-hosted and organized by the Massachusetts Rehabilitation Commission (MRC), Massachusetts Commission for the Blind (MCB), Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), and the Statewide Independent Living Council (SILC).

In understanding the challenges that many people living with disabilities have regarding transportation, organizers of the event transported and provided free hotel accommodations to individuals living with various physical and/or mental disabilities from all areas of the state of Massachusetts.

The theme for the two-day conference was "Moving Beyond the Barriers: Secrets to Successful Employment." The conference's goal was to make a difference within the lives of individuals living with disabilities by empowering and encouraging them to acquire the skills and tools that are essential to success within the workplace. Attendees could also take advantage of over forty exhibit tables within the halls of the hotel that featured various services available to meet the needs of individuals living with disabilities.

For any individual living with a disability, the Annual Consumer Conference is an event that everyone should attend at least once, if not every year. The knowledge gained from the conference is one that could potentially change your life in ways you never imagined. For me, as a person with a disability, it was an incredible opportunity to meet new people, learn about other programs that exist across the state, and to learn more about ways of successfully enabling employers to see past my disability.

Speak to your counselor at any of the previously mentioned commissions to learn how you can register for this two-day free conference next year! *Disability Issues* will also post a conference registration reminder in the Information Brief section of our newsletter.

Jamie Mello has a Master's degree in Social Work with a concentration in Health and Mental Health from Salem State University. She is currently completing her final summer internship at the National Association of Social Workers in Boston Massachusetts. After completing her internship, Jamie will begin her search for employment working with people with disabilities.